Minutes of September 4, 2001
Web-based Resource Center Work Group Conference Call

First names were requested to address each other during the current and future calls. Tom expressed that "Most of us are already familiar with each other with mutual respect inherent, and it should add to the comfort level of our work group dynamics."

Members participating on the call made brief introductions.

- Suzie Burke-Bebee, Centers for Disease Control and Prevention (CDC) / National Center for Health Statistics (NCHS)/ Office of Data Policy and Standards
- Henry Chao, Centers for Medicaid & Medicare Services (CMS)/ Center for Medicaid and State Operations
- Bob Davis, New York Statewide Planning and Research Cooperative System (SPARCS)
- Tom Doremus, Public Health Foundation (PHF)
- Marjorie Greenberg, CDC / NCHS / Office of Data Policy and Standards
- Vicki Hohner, Washington State Department of Health
- Hetty Khan, CDC / NCHS / Office of Data Policy and Standards
- Helen Regnery, Association of Public Health Laboratories (APHL)
- Ginny Van Horne, Academy for Health Services Research and Health Policy (The Academy)
- Michelle Williamson, CDC / NCHS / Office of Data Policy and Standards

Membership Overview
Tom provided an overview of the work group based on the responses by members to the membership profile template along with some personal observations.

"Half of our group served as interview respondents for the Consortium Education Strategy report developed by the Lewin Group and The National Association of Health Data Organizations (in conjunction with the Consortium's Education Work Group). Many of our experiences, perceptions, and nuggets of working knowledge went into the formation of the strategy. Nine members of our Work Group currently work with the Education Work Group, so we probably will maintain strong integration. (A note was made by Marjorie that this Work Group remains a 'standing group' but is currently inactive).

One of the areas we need to determine is educational issues that should be decided by the Web-based Resource Work Group. Having several members of other work groups within our own will help to solve this question. As I understand it, we will be focussing on the 'how, when and where' within the Web medium and determining/learning through practitioners and researchers in the field -- the best 'what' to present. The Education Work Group along with the contracted

partners has done an excellent job of helping define parts of 'how, where, when and what' for the Web and other communication mediums, as well as 'who and why.'

A third of our group has clinical credentials, many in the nursing profession, which should be helpful in making sure we address the needs of patients/clients as well as clinicians. It should also provide some essential perspective for clinician interaction with data suppliers, collectors, and users.

Our work group has a good balance of individuals that manage entire organizations, divisions, or departments along with front-line specialists and senior staff. This should aid in our design of a web-based resource center that addresses technical as well as strategic needs.

We have good Federal representation, with our team from the National Center for Health Statistics (Hetty, Michelle, Marjorie, and Suzie), and (Rachel and Henry) from the Centers for Medicaid and Medicare. We have good state health department representation, both from staff at state agencies (Bob and Vicki) and staff from ASTHO (Alana and Jeffrey). We also have strong representation from staff and leaders of other national organizations that serve public health at several jurisdictional levels and work to interface with data users, collectors, suppliers, decision makers, and funders (Denise - NAHDO, Ginny -The Academy, Helen – APHL, Walter – MHDI, William - NACCHO, and myself - PHF).

Some of us have good database skills, primarily with Access. A few of us have web development skills, at differing levels of expertise. A few have strong informatics skills and analysis experience with both large and small data systems. Some members have a working knowledge of web-based research for public health and health research needs. Members from the NCHS team and ASTHO team have a working familiarity with Knowledge-Management processes and HIPAA resources. Most of us have direct and indirect experience with the barriers and opportunities connected with data standardization.

Organizational resources include seed money from NCHS for conceptualizing this project and supporting conference calls, including staff and the Primary Consortium web site. Other members have Web development expertise and software, and systems programming capacity. Most of us have contacts external to the Consortium that we can network with on the issues.

We are strong in our academic training, work experiences, skills, and connections to Consortium work groups as well as in several/diverse areas of Public Health.

Regarding organizational staff that can add value to the member's contributions, three members have technical staff that may be able to assist us on information technology issues.

Advocacy is problem for those representing government agencies, non-profit organizations, or that are limited to a focus of membership driven goals. However, there is an opportunity to serve as advocates on Work Group issues for those able to represent themselves as individuals.

Other barriers are limited to individual members that may lack a working knowledge of specific data standards issues. This is a barrier that will start to dissipate over time as we all work through the issues.

Many of our members are working on two or more work groups and that is only counting their participation within the Consortium. Many stay well informed and likely receive five to ten communications a day from all the groups and committees they participate on. Our membership has already contributed in an amazing measure to the standardization mission. However, many appear to be loaded with responsibilities. Three to four members are only able to participate in the conference calls (with limited additional input). Those with more time appear to have on average no more than a couple hours per week. So that we do not court 'burnout' and still address our objectives, I believe we will need to set our priorities early, focus on the essentials, and be forgiving when members have competing commitments. Those who are unable to participate in future calls are requested to send in their bits of wisdom (either based on the agenda or minutes that follow meetings), especially on issues they have a working knowledge of.

Are there any comments on the overview or general comments at this time?" No comments.

Deliverables and Timeline
The NCHS team and Tom had worked out details on deliverables that they felt were necessary milestones that need to be reached to maintain momentum of the Consortium goals and to prepare the public health and health research community for time critical elements of HIPAA.

Tom asked that the participants discuss the deliverables to achieve consensus on the approach. "For the first deliverable we are attempting to meet a deadline of October 29. We want to come up with an inventory and categorization of the inventory of Web-based resources. This deliverable becomes a priority because of its deadline and position within the flow of work. Once we have an idea of what is out there, then we can start to determine how these particular sites affect the public health data processes and health outcomes." He asked that members volunteer according to their time availability by contacting him directly. Per Bob's suggestion and group agreement, Tom asked that the Work Group establish categories of sites, then he will work with the research volunteers in dividing-up

the categories as a starting point for direct site research. Bob also noted later in discussions that a role-based, versus subject-based category breakout should also be considered.

Tom: "Volunteers will be asked to research sites, and I will post links to these sites on a project page posted on the Web on a daily basis (when possible) so that contributors can be aware of the sites already reviewed and all members have an opportunity to link to them and make comments on their potential effect on the public health data processes and client outcomes."

Marjorie welcomed Henry, who is representing the Centers for Medicaid & Medicare Services (CMS) per Rachel Block's request, and asked "In developing the resources that CMS developed for Medicaid, did you do any type of inventory or scan of what was available or that was relevant to your work?"

Henry: "We polled primarily our customers on our products that we developed to meet gaps that existed in many of the states. These states are finishing up their assessments. The products focussed on awareness, education and assessment. Primarily, the resources for that come from the Systems Technical Advisory Group (our regional office systems contact).

We have an analyst, Sheila Frank, who serves as our eyes and ears. She brings back a lot of ideas, which we try to focus on. Recently, we completed two white papers, one on coding issues and one titled How Do You Determine If You Are a Covered Entity.

We have a list of Web-based resources in the model. We are currently developing version 2.1, which will come out September 30. This will be the third release in 6 months. There will be several resources within the model or linked via our toolkit. 60-70 links and products are identified in the model. A product could be a white paper, a crosswalk, a project management outline, etc. Washington Publishing Company posted a copy of the Medicaid HIPAA Compliant Concept Model at MHCCM.org. The list of resources is accessible via the toolkit at the site. Some products are also posted. The toolkit applies to several sectors in the healthcare industry."

Ginny: "Tom, are you envisioning an annotated list, where the links would include a description."

Tom: "Yes, a brief description along with the relationship to public health and client outcomes. We want to provide wording that gives practitioners, educators, and researchers a reason to learn more."

Vickie: "There are a lot of sites that have already pulled together HIPPA information."

Suzie: "My concern is that many of these sites are not public health focussed."

Vickie: "I am working with ASTHO and NACCHO to provide information for the 'GIVES' site."

Tom stated that the next deliverable was to develop an interim report by December 17, 2001 that would feed into a 'white paper' on the educational needs of public health practitioners and educators (specifically related to web-based media) on standardization issues.

As an aid in determining the structure of our future Web site and possibly the development of our paper, Tom asked Suzie to briefly discuss the nature of Knowledge Management as it pertains to online education.

Suzie: "Knowledge Management is, simply stated, organizing information and communicating it. It includes three separate areas: technology, organizational theory, and project management. From the technology side – architecture and networking, from organizational theory – the people involved, regarding project management – you want projects to be completed on time, within budget, and with the appropriate deliverables. You take the wealth of knowledge of individuals and organizations and make it accessible to others through technology. An example for HIPAA is SNIP's work, which they have done so well for the last 14 months or so. Knowledge Management can be a platform within an organization or on the Internet. Some of the tools that could be used on a Web site could be discussion boards, listserves, etc. It utilizes software and can be basic or elaborate and expensive. It can include search engines within a Web site."

Tom discussed the role-based approach, asking the participants. "Do we want to take visitors through a process of role to subject, or create a categorization by subject area and then parse out the different roles. Do we want to section out the Web site based on local issues, state issues, and national issues? Do we want to take the natural web approach, to provide navigation on all pages to go in several different directions based on visitor preference."

Bob: "I believe the answer is yes to all the above, but we should go with one for the interim report and allow people to comment. Let's also consider making an agenda item regarding the positives and negatives of role-based versus subject-based, make the decision within the Work Group, and write the paper. If people have enough comments to say that a different approach is better, then the paper will have served a purpose."

Suzie: "I agree, I think the content and the way we categorize it is going to drive the way that the Web site is used."

(NOTE: as a logistical consideration here, we are currently asking members to suggest and comment on categories. Please consider role-based versus subject based as well as HIPAA versus non-HIPAA for this process.)

Marjorie: "I am also in agreement in what has been said. One aspect of this deliverable, seeking direct input from practitioners and educators. We are hoping that with the diverse participants within this Work Group that they can find out what is most helpful from their stakeholders and constituents. However this is designed, and what content is contained, should be driven by the needs of the practitioners and educators. A structured way of gathering that input within each organization would be helpful. This could be done in a preliminary manner, then as Bob suggested, once the interim report is written, take it back to the Board of your organization, a group of interested people, etc."

Tom: "This sounds like it would be the best scenario we could ask for. Can we make this job easier for the organizations and agencies by coming up with a template of the type of information we are going after? This would provide a focus. With our deadlines coming so quickly, we probably want to steer this as best as possible."

Bob: "Do mean by steer it to make a decision and go."

Tom: "Yes, come up with some categories of information. I don't know if we can do this during the current call, but we could have a 'point person' take in suggestions for a basic template, then send it around on the listserve or place it on the Web and obtain a consensus. I believe it is important to obtain similar information from each organization."

Bob: "Henry, was the MHCCM organized by subject or role."

Henry: "We tried to collect as much material as we could as we went along. We are working on categories in a sense by building a 'user-friendly' front end in the toolkit so that users can find materials useful to them quickly."

Bob: "So you are in the process of developing your own categories."

Henry: "At first we did not have many, but with the site growing rapidly, it has become essential."

Bob: "Can you share the category ideas on work that you are currently engaged in."

Henry: "Sure"

Marjorie: "When you talk about a basic template are you talking about a template to determine what we need to know from their stakeholders and constituents and allow them to determine how to collect it."

Tom: "Yes"

Marjorie: "Some people will state that they need resources that are already accessible, but as Suzie suggested, they are not geared toward public health. They need some sort of front-end, interpretive piece, or be adapted to public health. By finding what is accessible along with what people feel they need will help define what we need to do to make the information useful for public health needs."

Suzie: "I spoke with Denise Love this morning about the MHCCM and how it could serve as a model for our needs. At the same time we need to look at the covered entities within the HIPAA legislation. We will have different people approaching the Web site for different reasons. Our challenge will be to, as Marjorie had described, to provide something at the front-end that would introduce HIPAA to certain people and at the same time, those who want to drill down into the information, that they will have that option. When we are looking at the Medicaid information at MHCCM there may be some crossover for public health, but we need to be careful."

Tom: "Regarding being careful, can you explain that further."

Suzie: "Vickie, does Washington State put together Medicaid and public health under one umbrella?"

Vickie: "Not in Washington, but this is done in different states and this can lead to different decisions."

Suzie: "Maryland puts their HIPAA information in a totally different location from where the Medicaid information is. Just as Maryland has purposely established a separate location, we want to be careful where we steer people."

Vickie: "What I think Suzie is talking about is HIPPA is going to drive some of the decisions for public health, especially where there are Medicaid connections, such as Medicaid providing funding to certain public health programs. HIPAA will start the process and we will have to build around it."

Marjorie: "I think that we have to remember that HIPAA brought us to the table and is helping to keep us there, but our responsibilities are broader. When we look at resources about how standards are developed and implemented, we want to look at patient medical record information standards, clinical standards that might not be in phase one of HIPAA, but are important standards for public health information. When Bob was talking about categories, two big categories

that came to my mind were HIPAA and non-HIPAA, such as administrative issues, transactions, code-set related issues, and privacy and security issues. In the non-HIPAA (or should I say 'beyond HIPAA'), material related to NEDSS, clinical standards, laboratory issues, (some of these relating to claims attachments). There are likely more sites related to HIPAA than non-HIPAA. The challenge will be to keep our focus broad, but meet people's immediate and long term needs."

Tom: "Marjorie, I am in agreement with you. Many people will see the value of HIPAA, but will want to have information that is important to them at the present. Meeting their immediate needs can be the vehicle that helps to warm them into HIPAA.

Vickie: "I agree with both of you. We have to get a better understanding of how HIPAA is going to affect and drive public health before we start going too far in other areas. I think that it is going to be more pervasive than people think it will be at this time. It would be difficult for us to have other efforts ongoing and then have them chopped down because there were HIPAA implications that were not considered, plus the fact that we know that HIPAA is not finished."

Henry: "How we started out our project in terms of determining matching information that we can produce and gather, information that people needed, what we did was took what we termed the Medicaid Enterprise – we have an enterprise view and an operations view. We felt that in looking at the commonality across the Medicaid programs, (the focus is usually on the diversity) but we identified about 280 common business practices that all 'Medicaids' have to engage in. My suggestion is that since public health is every bit as diverse as Medicaid, but there are some commonalties. Using the enterprise view, regarding how HIPAA impacts the public health arena, identify the agency players that would be affected by HIPAA. Then categorize the information based on their common day-to-day operations. Then see if we could gather enough information to support not necessarily a model, but some stream of information that is relevant to those particular players."

Suzie: "Henry, I think what you are saying is very valuable. As a reality check though, I think keeping in mind what we want to accomplish should be incremental and in steps. Our deliverables may be just the beginning framework. Henry, is the MHCCM the result of large resources?"

Henry: "No. There are only 2 FTEs working on this. We did leverage a lot of the work done for Y2K, in terms of inventory systems. Medicaid agencies understood where their outer edges laid in terms of overall state management of health care. We leveraged those types of documents and information that was collected for Y2K to serve as the basis for the framework. We started out small, piloting the model in Maryland, only identifying 7 common Medicaid practices, but as we spent more time, that number grew.

It is good that you have New York and Washington on the call and in the Work Group, that is where your real input and experiences are going to come from. They can tell you how these pubic health programs connect to each other and to the Federal side. That is where your framework is."

Marjorie: "This is a valuable conversation that we have. It relates to what we were talking about at the July meeting, to model the whole public health enterprise. It started with the Public Health Conceptual Model that CDC has developed. But it is not the whole picture. I think that this is one of the goals of the Consortium I think, but it is not something that we have the resources to fully complete."

Vickie: "Suzie, should I talk a little bit about the concept of what we are trying to do with the state government white paper?"

Suzie: "Yes"

Vickie: "What I am trying to do on a national basis is come up with a white paper around state government issues and HIPAA. Currently, state issues and programs are not well addressed. The focus now is on the traditional model of private payer and provider. State government programs are often different from state to state, and such programs are not mirrored in the private sector. We are going to have to help develop information. It will not just be there for us to use."

Henry: "I am more than willing to join your efforts and leverage your work by including it in our model. People keep looking to stretch the boundaries of what we call the Medicaid Enterprise; to include all HIPAA affected entities.   We will probably release new versions of the model every 60-90 days, with incremental improvements."

Vickie: "With our state government work group, we are not trying to provide answers, but we are trying to raise the issues that state governments need to consider, since the governments are configured differently from state to state and the politics are different from state to state affecting what can be accomplished."

Henry: "If in the interim, there are categorizations and additional white papers or other products that you want to put out in a timely manner, but do not have your framework done, I would be glad to include it in our next release of the model."

Vickie: "We are just in the early stages of coming up with a framework."

Henry: "We have a good user base for our model and can also place it on a CD ROM that is distributed to states."

Tom: "To move along in our agenda, number three of the Deliverables, Develop Web-based educational materials for helping public health data users determine if the HCSDR Implementation Guide is relevant to programs, Bob do you have some thoughts on how we should approach this. What are the base materials that currently exist, what type of presentation format do you think will work, what are next steps."

Bob: "First I would like to commend Michelle for bringing it all together so that we have a first draft out to the Work Group that is developing the implementation guide and to the X12 group that is going to be approving this guide.

I have been so busy getting the guide to where it is now; I have not yet planned next steps regarding education.

Tom: "Is there a location where other members can get a look at the draft?"

Bob: "We can send it out to the Work Group. There will be 4 parts to the book. The first part is front matter, which is in Word format (Michelle has taken the lead on this). The second part is technical matter, which I am working on with Steve Bass, of Washington Publishing, have developed (in pdf format). This will allow comment to make sure we have the technical specifications covered for everyone who wants to use the guide. We consider draft one as a place to start discussion. The third part is providing examples of using the technical specifications (a Word document). Eventually we will be talking to Steve Bass to provide all three, plus appendices, to create one implementation guide."

Marjorie: "I think that the third part is something that our Work Group can coordinate with, rather than to have lead responsibility. We have a related activity with NAHDO and Bob to begin to develop and conceptualize some educational materials for helping public health data users determine if the new guide is relevant to their programs. And, if so, how to begin the process of implementing the standards. Our thinking is that the educational materials may start off being posted on our Consortium Web site (since it is already running). We may want to have them posted on the MHCCM. Eventually it would be posted in the WRC. The development of these materials is not a function of our Work Group, it is more of a function of the HCSDR Implementation Guide Work Group in association with NAHDO." (Bob concurred).

Bob: "I like the keep-it-simple mindset. One of the nice things about the MHCCM is they have used an image to aid in navigation of the site. I would hope that as we develop our categories, the reporting guide, NEDSS, etc. we use images to aid in navigation."

Tom: "I agree with this and already use this in web site development. 'Image Maps' can be built into pdf as well as HTML pages on the Web. We can ask practitioners and educators about their interest in this area.

Regarding the 4th Deliverable, we will focus on that after the 2nd Deliverable. As noted before, I want to have volunteers contact me directly with time availability for the 1st and 2nd Deliverable. Those that do not have the time to assist on a task group, if you can at least contribute your ideas. They are valuable to us and your consensus on the issues is wanted.

Any comments at this point?" No comments.

Work Group Description and Charter
Tom: "Are there any comments on the description?"

Marjorie: "The mission of the Web-based Resource Center Work Group will be to track and disseminate on an ongoing basis the efforts related to (I would say standards development, implementation, and data integration).

At this point the other new work groups are taking forward the work (what was prioritized at the March 2001 meeting), from the Education Strategy. I see the Education Work Group as a standing group, but not active at the moment."

Bob: "I would agree with that. We are now dividing the work of the strategy."

Tom: "Any comments on the Background and Purpose?"

Marjorie: "…the Consortium Steering Committee has directed the Web-based Resource Center Work Group to facilitate and oversee the development of an Internet resource center. I would strike the word 'develop' from the sentence. We have another Work Group called the Secure Funding Work Group that Elliot Stone is the Chair of. We are hoping to work with Larry Bartlett, who facilitated the July 2001 meeting, in creating a business development plan that will identify some approaches for obtaining resources to support the work. Our group may develop some materials, but additional resources are needed."

Tom: "Members of our Work Group had identified web development capacity as well as software as being of potential use for our mission. There are parts of our planned site that we could develop and post (a work-in-progress) for review and comment purposes.

Regarding what we will support, does anyone see anything out of the bounds of our capacity, especially considering the time limitations of several of the members?"

Ginny: "I am concerned about the time investment and resources required to create a searchable site."

Tom: "There are a number of search engines that can provide a piece of their engine for use by an individual Web-site. There is software for creating search engines and in fact FrontPage (Microsoft Web development software) includes a pre-programmed search component that you can easily add to your Web-site. For our site, this may or may not be useful, based on the complexity of our site. The FrontPage component, in its simple form, may provide too many options for users to link to."

Marjorie: "The functions that I listed are what came out of the July meeting. Some are specific responsibilities for our Work Group and others are related activities."

Tom asked that members review the functions and make any comments they may have via the listserve, including where our responsibility lies.

Marjorie: "We may want to list under the functions the deliverables."

Tom: "I would agree and feel it would help others outside the membership know what we were focussed on. Should we include the timeline?"

Marjorie: "Probably, I think this will be iterative too. The timeline may be a little ambitious."

Suzie: "My idea of putting together the charter was to be more encompassing or broader than the deliverables. For instance, under function one, instead of saying that our Work Group would develop the educational materials, it could say we would work with the HCSDR Work Group. The perspective that I am trying to get across is to make sure that the functions were not just limited to the first phases of what we are doing."

Bob: "I look at our Work Group as the architect of the Web-site - putting the educational strategy on the Web. We can be the designers, but it is not reasonable to consider that this Work Group will do all the development."

Marjorie: "This Work Group is to conceptualize it, to prototype it, to determine what future users need. In the development of the education strategy there was a high level of support for this. Now we need to determine how to operationalize. The next level will be to operationalize."

Suzie: "Would we want to keep functions three, four, five and six and add a coordination/architect function?"

(Note: The participants decided it best to comment on this after Suzie had made some adjustment to the functions. It will be listed as an Action Item).

Call Schedule

After discussions on the schedule of conference calls to be held each month, the WG determined that Tuesdays, from 11am to 1pm would work best. Tom requested that all members e-mail him directly at tdoremus@phf.org to identify Tuesday dates starting in October, through December that are not good days for participation. From the responses he will forward the best Tuesdays each month to the NCHS team for scheduling of calls.

Future Agenda Items

Tom stated that the agenda would likely be driven by the deliverables and their deadlines. He requested that suggested agenda items be presented to the group at anytime via the listserve. No discussion on upcoming agendas.

Action items

1. Suzie will make modifications to the Charter, based on discussions during the call, by September 14th. Tom will send out to the listserve by COB September 14th for feedback from members by September 20th.

2. After discussions on the schedule of conference calls to be held each month, the Work Group determined that Tuesdays, from 11am to 1 pm would work best. Please email Tom directly at tdoremus@phf.org to identify Tuesday dates starting in October, through December, that are not good days for your participation. From the responses he will forward the best Tuesdays each month to the NCHS team for scheduling of calls.

3. Email categories to Tom of existing web-based resources that provide education and information on health data standardization issues. Some examples presented by Michelle include HIPAA versus Non-HIPAA. The HIPAA categories may include privacy and security; administrative data, transactions, and code sets. Non-HIPAA categories may include NEDSS, clinical standards, and laboratory. Tom will post the suggested categories as close to daily as possible at www.phf.org/consortium/wrcwg/categories.htm Please make your suggestions and comments on the suggestions by COB September 18 (I will include a 1-5 rating scale for the categories so members can rate the value of each suggested category). Comments to the suggestions will be posted on the same page.

4. Volunteers to research the sites with existing web-based resources are asked to contact Tom via email. He will identify and 'divide-up' the categories so that the research work may be shared among volunteers according to their time availability (and stated interest if applicable).

5. Suggest questions that will help us learn the educational needs of public health practitioners and educators on standardization issues specifically related to Web-based media (while determining on-line technologies accessible by them). Work Group members that have organizational membership are asked to consider checking with their membership to assist in development of the questions. Please reference the Education Strategy report to aid in the identification of target groups. Tom will post the suggested questions as close to daily as possible at www.phf.org/consortium/wrcwg/questions.htm. Please make your suggestions and comments on the suggestions by COB October 5. Comments to the suggestions will be posted on the same page.

Call adjourned